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UNIVERSITY OF ALBERTA

OUT OF POCKET COSTS FOR INDIVIDUALS WITH SPINAL CORD INJURIES

BY

DARLENE CHERYL NADANE

A THESIS

SUBMITTED TO THE FACULTY OF GRADUATE STUDIES AND RESEARCH IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE DEGREE OF

MASTER OF HEALTH SERVICES ADMINISTRATION

DEPARTMENT OF HEALTH SERVICES ADMINISTRATION AND COMMUNITY MEDICINE

EDMONTON, ALBERTA

FALL 1991

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FACULTY OF GRADUATE STUDIES AND RESEARCH

THE UNDERSIGNED CERTIFY THEY HAVE READ, AND RECOMMEND TO THE FACULTY OF GRADUATE STUDIES AND RESEARCH FOR ACCEPTANCE, A THESIS ENTITLED **OUT OF POCKET COSTS FOR INDIVIDUALS WITH SPINAL CORD INJURIES** SUBMITTED BY **DARLENE CHERYL NADANE** IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF MASTER OF HEALTH SERVICES ADMINISTRATION.

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ABSTRACT

This study presents the results of a survey questionnaire on out of pocket incremental direct costs for individuals with traumatic spinal cord injuries.

Seventy seven individuals responded to the questionnaire which asked for demographic, income and cost information. The cost categories included in the study were equipment, supplies, medications, nursing, personal care, homemaker, other, miscellaneous and education.

The study found that a majority of the respondents to the questionnaire had out of pocket expenses in at least one of the categories examined. The data also showed that there was substantial variability in expenses for all cost categories.

Expenses for employed and unemployed spinal cord injured persons were also examined. To determine whether there was a difference in out of pocket costs for these two groups. A t test found no significant difference in costs for employed and unemployed spinal cord injured persons.

The final question examined was whether there was any difference in out of pocket cost for the different levels of injury. A one way analysis of variance found no significant difference in expenses for the five groups defined by level of injury.

The study concluded that the majority of spinal cord injured persons had out of pocket incremental direct expenses and that these expenses are largely variable in all cost categories studied.

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CHAPTER I

Introduction

In the last decade there has been a growing awareness of the disabled person as part of our society and of the costs associated with that person living independently in the community.

A great deal of discussion has centred around the economics of disability (costs to the individual and society). Disability due to illness or injury is costly not only in monetary terms but in psychosocial and emotional terms as well. While money cannot decrease emotional pain it can be a powerful equalizer to assist the disabled person to overcome some of the barriers to independence. Brown, Gordon & Ragnarsson (1987) in their article on 'Unhandicapping the Disabled' discuss the benefits of adequate income for the disabled person. They suggest that many of the perceived disabilities are in fact only handicapping conditions that given adequate resources could easily be overcome.

"It is important to distinguish between disability and handicap" (Vargo, 1978, p.14), in order to fully comprehend the significance of the research on how resources, or lack of resources, create or remove handicaps. Examples of

environmental factors that can create handicaps are poor access to transportation and inaccessible housing.

Other authors have expressed similar opinions about disability and handicapping conditions. Goldiamond (1981) explains that a handicap may exist when a disability (the inability to carry out some of life's daily activities) "interacts with the environment to impede the individuals accomplishment of goals for work, education, or other major life activities" (p.102). The Urban Institute (1975) in a study of service needs for the disabled also noted that "there are severely handicapping environments as well as impairments" (quoted in Goldiamond, p.702).

Other studies have backed up the belief that many handicaps can be overcome given the appropriate resources . Studies that focused on the activity of disabled persons in relation to their access to transportation (Brown, 1983) or to electronic prostheses (Hartung, 1975) found that the availability of these resources increased activity of the disabled person. Brown (1983) also found that at one year post injury, access to private transportation increased the probability of employment from 0% to 50%. These results suggest that to some extent adequate income and resources can reduce the barriers faced by the disabled. Unfortunately there is not sufficient understanding of the relationships of resources on

handicapping conditions and the subsequent impact on disabled individuals. There is also little information on the resource needs and the associated costs for the disabled individual. This study was undertaken to determine if individuals disabled by traumatic spinal cord injury have out of pocket expenses that are related to their disabilities. It was hoped that some of the resource needs and the expenses associated with those resources could be identified and described in this study. For the purpose of this study individual out of pocket costs included were direct, incremental, recurrent, costs for a one year period, 1988.

Incremental costs refer to the economic burden, or expenses, that are "additional to those costs which would have been incurred in the absence of the impairment" (Jacobs & McDermott, 1989, p.159).

The categories of costs included in the study were: 1. equipment, 2. supplies, 3. medications, 4. nursing, 5. personal care, 6. homemaker services, 7. other, 8. miscellaneous and 9. educational costs directly incurred to an individual as a result of having an impairment.

Housing adaptations were also included under miscellaneous; however, because this is usually a one time initial expenditure and the category was not specifically labelled, only a few individuals reported this expense for 1988.

Problem:

Recently the disabled community has become more visible and more vocal in expressing their needs and ideas. Their right to a "normal" independent lifestyle is an outstanding issue at present (Symington, 1984). Additional expenses and reduced incomes associated with disability are factors often cited by disabled individuals as barriers to independence.

Adequate income support and independence for the disabled individual has become a compelling issue in Canada. Quality of life is a major consideration in the present evaluation of economic resource allocation and attaining independence is a large component of the quality of life issue.

Health care and social program costs have been evaluated and analyzed in Canada; however, evaluation of the financial impact of disability on a personal level has for the most part been ignored, except in relation to the employment issues.

In Canada the health care system covers most medical and rehabilitation costs for individuals; however, the vast majority of the Canadian public is unaware of the ongoing personal expenses imposed on a disabled individual once initial rehabilitation has been completed. Some of these ongoing expenses are supplies for bowel and bladder care, special equipment and personal care services.

Our society has responded to the needs of the disabled person by developing ad hoc fragmented assistance programs in a weak effort to care for those viewed as less able to care for themselves. Disabled individuals are often classified by our society as 'sick' or 'different' (Easter Seals Ability Council,1987).

Unlike some countries, such as the Netherlands, social programs in Canada are viewed as necessary burdens and not as entitlements. The paternalistic attitudes and numerous special facilities and programs designed to care for disabled individuals has created a "climate of dependency adopted by the general public, professionals and in some cases by disabled people themselves" (Easter Seals Ability Council, 1987, p.7).In fact most disabled people are not "sick" and they are quite able to function as active 'normal' consumers, given adequate financing to purchase needed services and equipment.

For the vast majority of disabled Canadians it seems that the condition of adequate income has not yet been met. In fact the majority of disabled Canadians live in poverty (Torjman, 1988). In 1986/87, the Canadian Health and Activity Limitation Survey (HALS) conducted by the Secretary of State in Ottawa reported that 63% of the disabled Canadians had incomes of less than $10,000 annually compared with 43% of nondisabled persons. Only 5% of disabled Canadians reported annual incomes greater than $30,000.

A number of factors contribute to the financial hardships experienced by disabled persons. Their poverty is most often related to problems with employment, especially gainful paid employment. Many disabled persons are under employed and therefore have lower incomes (Booth,1984;The Premier's Council on the Status of Persons With Disability, 1990). Handicapped people who are able to work and have secured employment earn substantially less than their able bodied counterparts (Booth, 1984).

Other factors, no less important, include decreased personal and family incomes and increased expenses. "Regardless of their level or source of income, most persons with any form of disability need to spend more money on items or services required for daily living" (Torjman, 1988, p.5).

Decreased personal and family income occurs as a result of; (1) the disabled persons loosing their employment or having to change to a less lucrative location and/or; (2) a spouse or family member giving up employment to provide needed care to the disabled person.

Levels of education also effect employment opportunities. Less education usually is related to fewer opportunities for employment, lower income levels and lower socioeconomic status. The Canadian Health and Activity Limitation Survey (1986) reported that there is a clear tendency for disabled

persons to receive far less formal education than do nondisabled persons. Unemployment and under employment means that a person must rely on others for support and/or on financial support programs or insurance.

Financial assistance programs are basically divided into two categories; work related and non-work related. Work related programs require that contributions be made by employees for a specified period of time before that person becomes eligible for the benefits.

Many individuals disabled by spinal cord injuries are young men (under 25 years of age) who have either not been employed or who have nor worked long enough to qualify for program benefits. Those individuals who are injured at work are usually provided some protection through workers compensation (WCB) or disability insurance benefits however, individuals injured outside of work often do not qualify for work related insurance benefits, even when they are employed.

For the disabled person the difficulties in finding employment are compounded by the numerous barriers that exist. Disabled Canadians labour force participation rates are lower than the national average. In 1983-1984 only 48% of disabled individuals were in the labour force versus a 75% participation rate for other Canadians (Profile of Disabled Persons in Canada, p.18-19).

Public policy and program development have become fragmented and complicated and admission or access to many programs is more often based on how a person was injured rather than on his or her need. The numerous uncoordinated assistance plans are set up both by the provincial and federal governments each with its own criteria, procedures and administration.

The issue of out of pocket expenses incurred by individuals who are disabled,as a result of their disability, is seldom addressed. Their financial needs are often inadequately dealt with through "add-on or top-up" approaches (Torjman, 1988) within an existing program. Other difficulties faced by persons requiring income support include the extreme complexity of the varied programs, the discretionary features and the low level of benefits.

The various program eligibility criteria are often created specifically for an identifiable target group with the result being that many individuals on the fringes of the target group fall between the cracks .

Qualifying for programs does not guarantee adequate assistance either, as rates of assistance for social programs fall well below the poverty line. Torjman(1988) in her book 'Income Insecurity' states "benefits are inadequate both in terms of absolute value (their actual levels) and relative value (their

value in relation to increases in the cost of living)" (p.2). She also discusses the various psychological and economic "traps" that keep people who are receiving social assistance poor.

The discretionary features provided for in many government programs also add to the complexity and inequity of the income security system, as exceptions to the rules are frequently made by social workers and management. This further results in personal, regional and provincial inequities.

While the income security system in Canada has been subjected to scrutiny, criticism and review little consideration has been given to the high costs incurred by individuals who are disabled. Proposals for reform of the present system seldom address the issue of additional costs to the disabled person, while cost studies focus on program, institutional or health care costs. There is a definitive need to provide the policy makers with empirical evidence that disabled individuals have additional financial burdens and that the present system of support is inadequate and inappropriate.

The timeliness of this study on individual costs is also reflected in the recommendation for a single entry support program included in The Premier's Council on the Status of Persons with Disability Action Plan, 1990. This recommendation has addressed many of the issues just discussed. The recommendation was made for a community

support unit, which would integrate existing government support programs with resource components that are still required, into one unit. This unit would represent a new method of assistance for disabled persons as it would function as a single consolidated unit with access to a full range of supports.

Faced with the numerous challenges just reviewed, it is not surprising that disabled individuals feel financial and service issues need addressing immediately. "Ensuring an adequate level of income for the disabled is probably one of the most effective ways of enhancing their sense of respect and dignity" (Obstacles, p.52). The question remains: What is an adequate level of income?

Definitions:

Salary: Income or wages received from employment.

Income: Any "money" received from various sources during a certain period and includes all sources such as financial assistance programs, employment, etc.

Out of pocket expenses: Cash paid out by the disabled individual for equipment, supplies, services, etc. required because of that person's disability.

Direct costs: Costs that are associated with the treatment of the disease or injury (Smart & Sanders, 1976).

Indirect costs: Implicit costs resulting from the ramifications of the disease or injury (Smart & Sanders, 1976).

Total out of pocket costs: The sum of all cost categories included in the questionnaire. The seven categories are; equipment, supplies, medications, nursing , personal care, homemaker, other (handyman services, home maintenance, occupational therapy and physiotherapy) and miscellaneous.

Incremental costs: The economic burden, or expenses that are additional, to those costs which would have been incurred in the absence of the impairment (Jacobs & McDermott, 1989).

Recurrent costs: Costs that are repeated such as supplies purchased monthly or yearly.

Spinal cord injury (SCI): An acute traumatic lesion of the spinal cord, including possible trauma to the nerve roots at the base of the cord, which results in varying degrees of paralysis and/or sensory loss below the level of the lesion (Smart & Sanders, 1976, p.104).

Paraplegic: "An SCI patient who has sustained a cord lesion at the second thoracic segment or below and is experiencing resultant paralysis and loss of sensation in the lower extremities (the extent of the paralysis and sensory deficit depends on the degree and location of the lesion)" (Smart & Sanders, 1976, p.104).

Quadriplegic: "An SCI patient who has sustained his cord lesion in the cervical region or at the first segment of the thoracic region and is experiencing resultant paralysis and loss of sensation in both the upper and lower extremities (the extent of the paralysis and sensory deficit depends upon the location and degree of the lesion)" (Smart & Sanders, 1976, p.104).

The World Health Organization provides these definitions of impairment, disability and handicap (as quoted in Easter Seals Ability Council ,1987,p.4).

Impairment: Any loss or abnormality of psychological, physiological or anatomical structure or function.

Disability: Any restriction or lack of ability to perform an activity

in the manner or within the range considered normal for a human being.

Handicap: A disadvantage for a given individual resulting from an impairment or disability that limits or prevents the fulfilment of a role that is "normal" (depending on age, sex, and social-cultural factors).

CHAPTER II

Literature Review

This chapter reviews literature that is relevant to the following topics: Spinal cord injury; description and demographics; cost studies on injury and illness; the methodology of cost studies and; studies on the costs of spinal cord injury.

Background information

Level of injury

In the neck region are eight spinal nerves and seven cervical vertebrae (C1-C8). Cervical 1 - Cervical 4 injuries, if complete, usually result in the loss of independent breathing and the need for a respirator in order to sustain life. Incomplete lesions at this level most often result in impairment below the chin (Buchanan, 1987). With cervical injuries there is no functional use of the arms, however some shoulder movement may be present at the lower level lesions (Alvarez, 1985; Buchanan, 1987).

In C5 to C8 injuries various arm and wrist movement is

present; however, finger function is still not present. The ability to balance the truck of the body may also be absent for injuries in this area (Alvarez, 1985; Buchanan, 1987). In the vast majority of cases, spinal cord injury in the cervical region whether complete or incomplete results in quadriplegia.

Injury in the thoracic region (T1-T12) results in paraplegia in most cases. The level of function is greatly variable depending on not only which thoracic level is injured but also on whether a lesion is complete or incomplete. There is a great deal of difficulty in accurately categorizing levels of injury due to the variability of function and neuromuscular damage (Bracken, Shepard, & Webb, 1981).

In addition to the altered movement resulting from spinal cord injury a number of other functional impairments may result. Some of these impairments are muscle spasticity, respiratory dependence, altered sexual function, chronic pain and loss of bladder and bowel control (Buchanan, 1987).

Demographics

Canada

In Canada most spinal cord injuries happen to young males between the ages of 21 and 30 years. For the years

1986 to 1988 this was true for 42.8% of the injuries (Injury Awareness and Prevention Centre News [IPAC News] 1991).

Motor vehicle accident is the primary cause of injury (47.7%) with recreational accidents, especially diving (15%) as the second most common cause of spinal cord injury.

The following statistics were compiled by the Canadian Sports Spine and Head Injuries Research Centre in Toronto and presented in the IAPC News-April 1991. "Spinal injuries in Canada occur more frequently in July (36.2%) and August (26%) than in any other months" (IAPC News, p. 13).

Cervical lesions in the 1986 to 1988 period were the most common (84.5%), thoracic lesions accounted for 2% and thoracic - lumber for 2%. No sacral injuries were reported.

Alberta

Alberta statistics,1990, provided by the CPA for individuals registered with the CPA show 41% were injured in motor vehicle accidents. If motorcycle accidents were included in this category it would increase to 58%. The secondary cause of spinal cord injury in Alberta was shown as industrial falls and accidents at 11.5%. Sports was listed as the cause in 11.5% of the injuries.

Fifty four percent of the injured were listed as paraplegic

and 46% were defined as quadriplegic. Seventy six percent were male.

United States

American statistics estimate that there are 120,000 to 150,000 spinal cord injured persons in the United States and each year 8,000 to 10,000 more are added (Gordon & Stevens, 1981; Weinberg & Solot, 1985). The spinal cord injured population in the U.S.A. is mostly young male, with a male to female ratio of 4:1. The average age is 29.7 years, the median age is 25 years and the mode is 19 years (Parsons & Lammertse, 1991). Sixty one percent of the spinal cord injured population are under the age of 30 years (Gordon and Stevens, 1981). The prevalence (number of SCI at any given time) is estimated to be 700 to 800 per million population by DeJong & Batavia (1991), and as high as 906 per million persons at risk by Parsons and Lammertse (1991).

The major cause of injury in North America is motor vehicle accidents. Sports is listed as the secondary cause at 16%. Eighty two percent of those injured are males.

Education levels at the time of injury are listed by Young, Burns, Bowen and McCutcheon (1982). Fifteen percent had grade 8 or less, 28% had some high school, 34% finished high

school and 24% had some post secondary education.

Sixty percent were employed at the time of injury, 20% were students, 12.5% were unemployed and 8% were listed as retired or homemakers.

Cervical spinal cord lesions account for slightly more than half of all new injuries; thoracic injuries account for more than one third and lumber-sacral vertebra lesions account for the remainder (Stover & Fine, 1986).

Cost of Illness Methodology

Background

Calculating the economic costs of illness and injury is a relatively new area of research going back approximately 20 years.

The first studies addressing the issue of economic costs for disease and illness appeared in the late 1950's and early 1960's. Fein (1958) published a book on the economics of mental illness. In 1959, Mushkin and Collings, wrote an article an economic costs of disease and injury. In 1961, Weisbrod described general methodologies of cost in his book,

Economics of Public Health, and in 1965, Klarman wrote on Syphilis control programs.

Mushkin and Collings (1959) were the first to describe economic costs. They defined economic costs as costs that "arise out of the impact of disease and injury upon economic resources" (p.795). That is: How do injury and disease affect the distribution, use and availability of economic resources?

In 1966, Rice published an article which described and applied a methodology for estimating costs of major disease categories. This study is considered to be a landmark study by researchers in the area of disease and injury costs (Hartunian, Smart & Thompson, 1980).

Cooper and Rice (1976), published an updated methodology for estimating costs titled, 'The Value of Human Life Revisited' which serves as a reference point for present research.

Numerous studies have applied economic illness and injury costs methodologies in the 1970's and 1980's. Some of these include, McCollum (1971), Smart & Sanders (1976), Hyman (1977), Bodkin, Pigott & Mann (1982) and Jacobs & McDermott (1989).

Relevance of Cost Studies

Estimating the economic costs of disease and injury has been necessitated by recent advances in health technologies (Hartunian, Smart & Thompson, 1980). The rapid growth in technology especially in the last thirty years has resulted in multiple and infinite demands for finite resource allocations. Choices for preventive, diagnostic, therapeutic, rehabilitative, or follow-up service have profound effects on overall resource allocations (Battista, Spasoff & Spitzer, 1986; Eckenhoff,E.A., 1991). Questions constantly arise as to how resources can be best allocated or used most efficiently and effectively. Governments and the public are expecting more health care for all people while controlling costs and increasing accountabiliity for health care professionals. The mounting pressures for good decisions are resulting in an overwhelming requirement for the information acquired by research (Hartunian, Smart & Thompson, 1980).

In the United States, as recently as the 1940's (before antibiotics), about 75% of individuals who survived spinal cord injuries died within a few years (Eckenhoff, 1981). Today, because of medical advances in treatment and technology, life expectancy is almost "normal" (Kraus, Franti, Riggins &

Borhani, 1976; Eckenhoff, 1981). Concomitant with longer life expectancy is the increased cost to the individual and society.

Another critical reason for studying costs of injury and illness relates to the development of policy by governments. Issues relevant to person with spinal cord injuries and related disabilities are compelling (DeJong & Batavia, 1991). Information provided by researchers can influence assumptions and decisions made by policy makers in all levels of government (DeJong & Lifchez, 1983).

Presently policy makers are provided with numerous cost studies for programs. The emphasis for many of these studies is on the high costs to government budgets. Expenses incurred by individuals with disabilities are private and concealed from public view (Jacobs & McDermott, 1989). Research is scarce in this area and Canadian incremental cost studies could not be located.

DeJong and Batavia (1991) are prominent authors in the area of health services and spinal cord injury research. They contend that increased survival and prospects for an independent and productive life for spinal cord injured persons require a comprehensive research agenda in this area.

Health Services Research

Along with health care economists are a second group of professionals who are contributing to the body of knowledge on costs and effective use of resources in providing health care services. Physicians and allied health professionals largely compose the health services research community at present. This leaves some researchers to argue that other disciplines are needed to fully comprise advanced and comprehensive research in this relatively new field (DeJong, Batavia & Griss, 1989; DeJong & Batavia, 1991). More specifically, health services researchers are concerned with issues of cost, access, quality, efficiency and effectiveness of health care services (Flook & Sanazaro, 1973).

While there is a growing interest in areas related to physical disability, it is felt that certain areas of research are still at a very rudimentary level (DeJong & Batavia, 1991; Fuhrer, 1988). Especially notable is the scarcity of research on the health care needs of persons with spinal cord injuries after initial emergency, acute care hospital treatment and rehabilitation. Recently there has been a number of articles appearing in the literature on the need to develop health services research especially in the area of physical disability.

While the need for research on costs is not in dispute, there has been disagreement and considerable debate over the methodology that is used when the cost of illness or injury is being evaluated (Rice & Hodgson, 1982). Expenses associated with a disability can be examined in a number of ways and the method of assigning dollar amounts to lost productivity and human life is probably the most contentious issue in cost evaluation studies.

The most commonly applied method at present is assigning costs into one of two principle categories ; direct or indirect costs. Direct costs are those associated with the treatment of the injury or disease (Smart & Sanders, 1976). Direct costs are explicit costs and are reasonably easy to identify and assign dollar values to. Direct expenses include emergency medical and rehabilitation care as well as follow up care and treatment (Smart & Sanders, 1976; Rice, 1966).

Indirect costs are more implicit in their association to treatment of a disease or condition. Indirect costs result due to the ramifications of the condition or disease. Most significant of these is the lost output of an individual sustaining premature death or disability (Smart & Sanders, 1976).

Cost studies for spinal cord injury

In 1970, David Barrie estimated that the life long costs resulting from a traumatic spinal cord injury were about $320,000. Costs included in his study were initial hospitalization and rehabilitation, home adaptations, rehospitalization and foregone earnings . Shorty after Barrie's study was published, Dr. J. Young (1972) provided estimates of costs for spinal cord injury in a report from the Southwest Regional System for Treatment of Spinal Injury. He suggested that a range of $175,000 to $350,000 was appropriate for total costs associated with spinal cord injury (Smart & Sanders, 1976). Unfortunately the costs he included in his estimate were not available so comparisons with other studies cannot be made. More recent estimates by Humphreys (1978) have been at $350,000 to $600,000 for a quadriplegic's and $200,000 to $400,000 for a paraplegic's lifetime care costs.

The direct and indirect costs of spinal cord injury (SCI) have been examined in detail by Smart and Sanders (1976). In their study total costs for SCI were broken down into direct and indirect costs. The direct costs they included were initial hospitalization and rehabilitation immediately following injury as well as costs of medical maintenance services normally

required by an individual for the rest of his or her life. Indirect costs included in this study are foregone output, lost earnings, administration costs of insurance companies and government agencies and the legal and court costs associated with litigation.

This study was possibly the most comprehensive in costs covered, both direct and indirect for spinal cord injured persons; however, because of the macroscopic approach little consideration was given to personal costs.

The most recent study published by Walsh (1988) describes costs of spinal cord injury in Australia. This study uses a different methodology than was used by Smart & Saunders (1976) to categorize costs. Three major headings were used for cost identification; initial hospitalization, income support, and ongoing care. Initial hospitalization was considered to be an initial cost and income support and ongoing care were grouped under ongoing costs. Figures on costs were presented as best estimates of several experts and found to be consistent with the literature (Walsh,1988). The studies' objective was to estimate actual costs. Opportunity costs and other indirect costs were not included in their total cost estimation. Individual out of pocket expenses were not specifically addressed in this study, however there is no way of knowing for sure which costs

would be specific to the individual and or family.

Other studies have been completed on costs associated with spinal cord injury. These studies by Ross (1974) and Matlock (1974) were analyses of the most cost-effective methods of treatments and did not address the issue of total costs.

CHAPTER III

Methodology of the Study

The following chapter provides a description of the development of the questionnaire, the sample selection process and methodology used in this study. It was decided that for economic reasons the best method of collecting the required information would be by use of a survey questionnaire (Kawash & Aleamoni, 1971). No Canadian work has previously been published relevant to this area, therefore a questionnaire had to be developed.

For the purpose of this research study on individual out of pocket costs due to spinal cord injury a questionnaire provided several advantages. A large number of individuals, spread over a large geographic area (Alberta) are easily contacted by mailing out questionnaires enabling the collection of large amounts of data economically (Berdie & Anderson, 1974). Mail questionnaires are also more convenient to complete as individuals can fill in questionnaires at their own pace (Berdie & Anderson, 1974).

While the convenience of being able to complete a questionnaire at one's own pace is an advantage, a major limitation is slowness of response (Berdie & Anderson, 1974).

Other major limitations of concern are lack of response and poor quality of response (Berdie & Anderson, 1974). These are discussed in more detail under limitations.

Development of the questionnaire from scratch necessitated that it be tested for validity. It was decided that the most appropriate tests for this questionnaire were tests to establish face and content validity.

Validity is stated to "mean that the program or instrument does what it claims to do" (Rubinson & Neutens, 1987, p.162). For this specific questionnaire, validity would mean: does the questionnaire measure all the costs and income sources relevant to each individual with a spinal cord disability? The two types of validity that were of concern for this project were face validity and content validity.

Face validity is the extent to which the instrument (questionnaire) "appears to be logically appropriate" (Seaman & Verhonick, 1982, p.238). While face validity is very much a subjective judgment and is therefore considered scientifically weak, it remains critical that it be addressed as it is very important that the questionnaire "be relevant to the respondent" (Rubinson & Neutens, 1987, p.99). In order to procure valuable, accurate information, respondents must be included to fill out the questionnaire and be able to understand the questions asked.

Content validity is the second type of validity of interest for this project. Content validity is concerned with the study's sampling adequacy, that is the, "examination of all possible questions and observations that potentially could have been used to measure the characteristics under study" (Seaman & Verhonick, 1982, p. 237). For this project, it was important to establish that representative cost variables be included as well as representative income sources.

Development of the Questionnaire

Once the research questions of the study were defined, a number of questions were developed. In order to ascertain all cost areas relevant to a spinal cord injured person and to identify all income supports from employment and government programs, several interviews were carried out. Secondly, a cost analysis form was obtained for the Canadian Paraplegic Association (CPA) that is used for litigation purposes to ascertain costs associated with an injury when an individual is suing for compensation of injury. This form, although biased in favour of maximum costs, was found to cover all areas suggested by the experts plus many more.

A major area of costs that were not addressed in this study, is the area of indirect costs. Only incremental, direct recurrent costs paid out by an individual such as equipment,

supplies, personal care and maintenance costs were included.

Interviews carried out previous to the questionnaire development included associations and individuals that had a vested interest in the research. Some of these included the Canadian Paraplegic Association, Easter Seals Ability Council, and the Premier's Council on the Status of Persons with Disabilities.

Once the draft questionnaire was completed, it was circulated to the same individuals previously interviewed plus four additional individuals who are considered knowledgeable in related fields, as well as the three professors who are supervising the research project.

The questionnaire was hand delivered (in the interest of time) to fifteen subjects who had spinal cord injuries and are possible respondents to this study. The various consultants were provided with the questionnaire and a list of evaluation questions before an interview was held. The interview consisted of reviewing the individual questions as well as comments made on the evaluation question form. Agreement and/or disagreement for each question was noted and comments on format, structure and additional content suggestions were documented.

Data and Methods

The validated survey questionnaire was then mailed to 500 Alberta residents who were members of the Canadian Paraplegic Association (CPA), Alberta division.

CPA maintains a client registry. They provide counselling advocacy information and referral services for all individuals registered with the association.

Sample Selection

The sample of 500 was randomly selected by computer from the total population (1560) of individuals living in Alberta who are registered members of the CPA. Recipients of the questionnaire may have been of any age, gender, marital status, socioeconomic status or race. All levels of injury were included.

Individuals with spinal cord injuries that reside in Alberta but who may not be registered with the Alberta division include two groups: those who moved to Alberta after being injured and those who were injured before the Alberta division of the CPA was founded in 1961. These persons would not be included in the population sampled.

Instrument and Data Collection

The final questionnaire, which is one page in length, was condensed from an original seven page questionnaire. The original questionnaire was validated for face and content validity. It was necessary to limit the length of the questionnaire to encourage individuals to take time to fill out the questionnaire. It was felt that a lengthy questionnaire would decrease response rates.

While most questions from the original questionnaire remained unchanged, except for smaller type and minimal rearrangement, two questions had to be deleted. The appendix to the questionnaire that provided examples of items in each expense category was also omitted in order to attach a covering letter (Appendix A).

No follow up was done as the responses were anonymous and there was no way of tracking non respondents. The cost of doing a follow up was also a consideration in not carrying one out.

A self-addressed, stamped envelope was also included on the back lower portion of the questionnaire. It was included in order that recipients of the questionnaire have minimal bother and no expense in returning the questionnaire.

The questionnaire (Appendix B) was made up of multiple choice questions and open-ended questions requiring specific

answers such as those requesting dollar amounts for expenses in 1988. The first section of the questionnaire requested personal information such as age, sex, marital status, accommodation, employment and income. The inclusion of demographic information was needed for comparison of the sample data to the population; ie. age, sex, how they were injured, level of injury and level of education. Employment status and level of injury information was also needed to answer the research questions posed in this study. Employment status is the independent variable used to answer the question: Is there a difference in out of pocket costs for employed and unemployed individuals? It was suggested that employed individuals may have different (higher) expenses than unemployed persons.

Question 7 asked for level of injury to be checked off according to categories such as cervical 1 to cervical 4 which equates with what is commonly referred to as a high level quadriplegic. Question 8 asks whether the spinal cord lesion was complete or incomplete. The combination of level of injury and type of injury provides some indication about the general level of function for that individual. It was postulated that the higher the injury (less functional ability) the higher the costs would be.

The second section of the questionnaire requested dollar

amounts for expenses paid out of pocket for specified categories. The categories were equipment, supplies, medication, nursing, personal care, homemaker, other, miscellaneous and education.

The category 'other' was defined as handyman services, home maintenance, occupational therapy and physiotherapy expenses exceeding coverage. Miscellaneous was undefined and education cost specified that expenses over and above usual costs such as tuition and books should be reported.

The final section of the questionnaire requested that recipients check off sources of financial assistance or other forms of assistance such as equipment supplies and services not usually received.

Income sources listed included Assured Income for the Severely Handicapped (AISH), Workers Compensation Board (WCB) benefits, private insurance, Canada Pension Plan (CPP), Social Assistance, and other. Other included personal income from other sources such as investments or interest on savings. This question was felt to be important to see if persons with out of pocket expenses may be receiving different income benefits than persons with no reported out of pocket costs.

Data Analysis

The raw data was organized onto a computer spreadsheet program for analysis. Descriptive statistics were used as well as a t test and an analysis of variance to answer the following research questions.

Research question 1:

Do individuals with spinal cord injuries have out of pocket cost specifically incurred as a result of their disability? Descriptive statistics were used: means, medians, frequencies and ranges for cost categories and total cost (Pagano, 1986).

Research question 2:

Do employed persons have different total costs than unemployed persons. For this question an independent t test was used to compare the difference in mean costs in the two groups (Pagano, 1986).

Research question 3:

Are there differences in out of pocket costs for the different levels of injury? A one-way analysis of variance (ANOVA) was selected to ascertain if any differences existed in out of pocket expenses for the five groups (Pagano, 1986).

CHAPTER IV

Results

This chapter presents the results obtained in this study. Results are presented in the following order: descriptive statistics for the out of pocket expenses of the sample (N=77), analysis of variance for total out of pocket expenses by level of injury and t test results for comparisons of total out of pocket expenses for employed and unemployed individuals.

The number of individuals responding to the questionnaire was 90 out of 500 or 18%, however only 77 out of the 500 or 15% of the responses were used. The responses not included were individuals under 18 years of age or individuals with disabilities identified as other than spinal cord injuries.

Characteristics of the Sample

Demographics

The sample was 87% male (n=67) with a mean age of 43 years (median=39, range=20 to 73, mode=39). Thirty six percent were 35 years and younger while 8% were over 65 years.

The mean age for the ten (13%) females in the sample

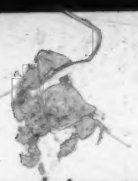
was also 43 years of age (median=46, range=21 to 61, mode=32). Four (40%) of the females were under 35 years of age while none were over 65 years.

Thirty one (46%) of the males were married or common law and five (50%) of the females were married or common law at the time of answering the questionnaire.

In this sample thirty one (40%) of the respondents had a college or university level education, thirty five (45%) had high school education (Grades 10 to 12) and the remaining seven (9%) had Grade 9 or less.

Of those 31 individuals having some post secondary education four (13%) made over $50,000 per year, five (16%) had salaries of $30,000 to $39,999 per year, six (19%) reported incomes of $20,000 to $24,999 and six (19%) had incomes of less than $10,000 per year. Ten (32%) of those with college or university level education reported no salary from employment.

In this sample twenty six (36%) of the respondents were employed. The forty nine (64%) that were unemployed received incomes from various assistance plans including, Alberta Income for the Severely Handicapped (AISH), Canada Pension Plan (CPP), Workers Compensation (WCB), Social Assistance Plan (SAP) and private insurance plans. Some individuals received financial assistance from more than one program or plan and a number of individuals received



assistance in the form of equipment, supplies or services.

For the 61 individuals individuals receiving non salary incomes from AISH, CPP, WCB, Social Assistance and private insurance, thirty (49%) received less than $10,000 per year, nineteen (31%) received between $10,000 and $25,000 per year, eight (13%) received between $25,000 and $40,000 per year and four (7%) received greater than $40,000 per year. Eleven of the 61 individuals received salary and non salary income. For the eleven persons reporting combined incomes of salary and non salary, five (45%) had incomes of less than $20,000 per year. Three (27%) reported combined incomes of $20,000-$30,000 per year and the remaining three (27%) reported combined incomes over $30,000.

Overall forty one (83%) of unemployed disabled individuals had incomes of less than $20,000 and seven (27%) of employed disabled individuals had salaries of less than $20,000.

Disability

Six (8%) individuals had lumber level lesions (L1-L5), twenty two (29%) had thoracic lesions (T1-T12) and thirty six (47%) had cervical lesions (C1-C8). Of the cervical lesions, six (8%) were in the C1 to C4 range. Thirteen (17%) of the respondents did not complete this question, therefore, their

level of injury is unknown.

Table IV-1 shows the number and percent of all respondents (N=77) who reported total expenses in each cost category. There were twenty individuals who reported zero expenses. The largest number of respondent, thirty three (43%) reported costs in the 1-2000 dollar range. The third largest number of individuals, eleven (14%) reported total expenses in the 2001-4000 dollar category. Four (5%) reported total expenses in the 4001-6000 dollar category and nine (12%) reported total expenses in the over 6000 dollar category.

Table IV-1

Frequency and Percentage of Persons Reporting Total Expenses in Each Expense Category

Expense Categories in Dollars	Individuals Reporting Frequency and %	
0	20	26
1-2000	33	43
2001-4000	11	14
4001-6000	4	5
>6000	9	12

Category amounts and percentages discussed in this section are summarized in Table IV-2. All dollar amounts are reported for a one year period in the year 1988.

TABLE IV-2

Description of Expense Categories

Category	Frequency	%	Mean in $	Range in $
Equipment	38	49	3129	36950
Supplies	27	35	478	1690
Medication	27	35	390	1575
Nursing	1	1	1100	1100
Personal Care	13	17	4136	16800
Homemaker	8	10	545	1100
Other	18	23	698	2455
Miscellaneous	25	32	3974	81970
Education	4	5	575	1100

Descriptive Statistics

Results for the total sample (N=77) show that a large majority (74%) of the respondents have out of pocket expenses. Approximately one quarter (26%) of the total sample reported zero out of pocket expenses. For those individuals reporting out of pocket expenses, the range for all categories combined was $75.00 to $119,800.00 for the year 1988. Total out of pocket expenses for the 77 repondents was $308,657.25. The average cost per person was $4008.54.

The largest out of pocket expenditures was in the category of equipment at $118,912.00 per year. The average cost per person in the equipment category was $3129.26 per year. Thirty eight respondents (49%) reported equipment costs ranging from $50.00 to $37,000.00.

The category miscellaneous had the second highest expenditure with a sum of $99,275.00. This category included some costs for housing adaptations if they were completed in 1988.

The average miscellaneous cost per individual was $3,971.00 for the year. In this category the sum and the average were higher because one person reporting housing adaptations of $82,000 was included. This was the only housing adaptation cost reported in 1988. The range of expenses reported in the miscellaneous category was $30.00 to

$80,000.00 for the year 1988.

Personal care was also a large expense category. A sum of $54,000 in out of pocket expenses were reported by thirteen respondents (17%). The average cost was $4,153.00 per individual. Of those having personal care costs, nine respondents (69%) were single and all were male except one.

Supplies totalled $12,918.25 (4.2%) of the total expenses with an average of $478.45 per person. Twenty seven (35%) respondents reported out of pocket expenses for supplies.

The category of other costs includes expenses for yard or home maintenance and/or physiotherapy and occupational therapy not covered by Alberta Health Care. Other expenses totalled $12,568.00 with an average of $698.22 per person. Eighteen (23%) respondents reported having other expenses with a range from $45.00 to $2500.00 per year.

Medications was the sixth category with a total dollar sum of $10,543.00 reported by twenty seven (35%) respondents. The average medication costs per individual was $390.48 per year and the range was $25.00 to $1600.00.

Homemaker costs were reported by eight (10%) respondents for a sum of $4,356.00. The average homemaker cost per person was $544.50 per year and the range was $100.00 to $1200.00.

Table IV-3 shows expense categories for two groups ,

employed individuals and unemployed individuals. The group designated unemployed includes individuals seeking employment as well as those not seeking employment such as retired persons, students or those who may have given up looking for gainful employment.

Table IV-3

Frequency and Percent of Individuals that have Expenses in Each Category by Employment Status

Out of Pocket Total Expense Category in $	Employed		Unemployed	
	Freq.	%	Freq.	%
0	3	12	6	33
1-2000	10	38	23	47
2001-4000	7	27	4	8
4001-6000	1	4	2	4
>6000	5	19	5	10
mean	3,547.96		4,386.77	
median	1,967.50		450.00	
range	18,550.00		119,800.00	

Group I, individuals who are employed, has twenty six respondents reporting. Three (12%) reported zero out of pocket expenses. The largest number of individuals, ten (38%) reported expenses in the $1-$2000 range with $600.00 being the smallest amount reported. In the $2001-$4000 range, seven (27%) reported out of pocket expenses. One (4%) reported expenses in the $4001-$6000 range and five (19%) had out of pocket expenses greater than $6000.

The dollar range for the employed persons out of pocket expenses was $0-$18,500 with an average of $3,547.96 per person. The median was $1,967.50.

Group II, designated unemployed, had forty nine respondents. Six (33%) reported no out of pocket expenses and thirty three (47%) reported expenses in the $1-$2000 range. Of those reporting expenses greater than $2000, four (8%) reported expenses in the $2001-$4000 range, two (4%) had expenses in the $4001-$6000 range and five (10%) had expenses greater than $6000.

If $0 and $1-$2000 categories were combined, fifty percent of the employed individuals have expenses of less than $2000, while eighty percent of those who are unemployed have expenses of less than $2000.

The average per person in the unemployed group was $838.81 dollars higher that for the the employed group; however, the median for the unemployed group was substantially lower at $450.00 versus the employed group median which was $1,967.50.

Description of Respondents Reporting $0 Expenses

Twenty (26%) of the respondents reported having no direct recurrent out of pocket expenses, in the categories specified for this study in the year 1988. Of these twenty individuals, eight (40%) received Assured Income for the Severely Handicapped (AISH) and four (20%) received Canada Pension (CPP). One individual received Social Assistance. Four (20%) individuals had income from employment, however, two of these four had reported incomes of less than $5,000 per year, the third had reported salary in the range of $30,000 to $34,999 and the fourth was in the $45,000 to $49,999 salary range. The remaining three persons had incomes from combined sources such as, insurance and salary or CPP and AISH.

Twelve (60%) of individuals reporting zero expenses were single. Eighteen (19%) individuals lived with someone and eleven (60%) of these lived with a family member. Only one (5%) individual lived alone.

For the twenty (26%) individuals reporting no specified expenses in 1988, two (10%) individuals had injuries at the cervical 1 to cervical 4 level, four (20%) individuals had injuries at the cervical 5 to 8 level, three (15%) individuals were injured in the thoracic 1 to 6 area, three (15%) individuals had injuries in the thoracic 7 to thoracic 12 area , and three (15%) individuals were injured at the lumber 1 to lumber 5 level . Five (25%) individuals did not fill in this question so the level of injury was unknown. These data are presented in table IV-4.

Table IV-4

Frequency and Percent of Persons with No Expenses and Persons with Expenses by Level of Injury

Level of Injury	Persons with $0 Expenses		Persons with Expenses	
	Freq.	%	Freq.	%
C1 - C4	2	10	6	8
C5 - C8	4	20	30	39
T1 - T6	3	15	16	20
T7 -T12	3	15	6	8
L1 - L5	3	15	6	8
Unknown	5	25	13	17

Table IV-5

Frequency and Percent of Persons with No Expenses and Total Sample by Age and Sex

	Individual with $0 Expenses		Sample(N=77)	
Age in Years	Freq.	%	Freq.	%
<35	6	30	24	31
35-59	12	60	45	58
≥60	2	10	8	10
Sex	Freq.	%	Freq.	%
Male	17	85	67	87
Female	3	15	10	13

The age and sex of the respondents reporting zero expenses is shown in Table IV-5 along with the age and sex of the sample population. Table IV-5 shows that age and sex of persons with no reported expenses is representative of the age and sex of the sample.

t Test for Comparison of Out of Pocket Expenses for Employed and Unemployed

The t test for independent groups was chosen to compare out of pocket expenses for the two groups: employed and unemployed. The null hypothesis is that there is no difference in the mean costs for the two groups as Ho: $\mu 1=\mu 2$. The alternate hypothesis there is a difference in the mean costs for employed and unemployed groups H1: $\mu 1 \neq \mu 2$. The alpha level chosen was 0.05.

There were 26 respondents in the employed group with a mean of $3,547.96 and 49 respondents in the unemployed group with a mean of $4,493.77 ($t=-0.266, df=73, p=0.79$). The null hypothesis was not rejected and it was concluded that there was no significant difference in the average cost per person in the employed and unemployed groups in this case.

Table IV-6 shows the group, level of injury, the number (n)

in each group and the frequency and percent of individuals in each out of pocket expense category.

Table IV-6

Frequency and Percent of Individuals by Level of Injury and Total Expense Categories

Group	Level of Injury	Total Expense Category in $	Freq.	%
I	C1-C4 (n=6)	0	2	33
		1-2000	3	50
		2001-4000	1	16
		4001-6000		
		>6000		
II	C5-C5 (n=30)	0	4	13
		1-2000	14	47
		2001-4000	5	17
		4001-6000	1	3
		>6000	6	20
III	T1-T6 (n=16)	0	3	19
		1-2000	8	50
		2001-4000	1	6
		4001-6000	2	12.5
		>6000	2	12.5
IV	T7-T12 (n=6)	0	3	50
		1-2000	2	33
		2001-4000		
		4001-6000	1	17
		>6000		
V	L1-L5 (n=6)	0	3	50
		1-2000	1	17
		2001-4000	2	33
		4001-6000		
		>6000		

In group I, five (83%) of the six individuals with injuries at the C1-C4 level had out of pocket costs under $2,000. Two individuals (33%) reported zero expenses and these individuals are included in the less than $2,000 category. The remaining one(17%) person had out of pocket expenses between $2001 and $4000. The average amount of out of pocket expenses for this group was $687.17 per individual.

For the largest group of individuals (n=30) with C5-C8 injuries, group II, eighteen (60%) had out of pocket expenses of $2,000 or less. Four (13%) individuals reported zero expenses and these individuals are included in the less than $2,000 category. The next largest proportion of individuals in this group, six (20%) had out of pocket expenses greater than $6,000. Five (17%) had out of pocket expenses in the $2001-$4000 category and one (3%) had expenses in the $4001-$6000 category. The average out of pocket costs per individual in this group was $6,934.90.

For group II the average was skewed as one individual reported housing adaptation costs of $82,000.00 resulting in a total expense of $119,800. If the $119,800 is not included then the average per individual in this group was $3,043.00. The average cost per individual with C5-C8 level injuries is still much higher than for the group of individuals with C1-C4 level injuries.

Group III had sixteen respondents with injuries in the thoracic 1 to thoracic 6 range. The largest portion of individuals, eleven (69%), had costs under $2,000. Two (12.5%) individuals had out of pocket costs in the $4,001-$6,000 range and the same number, two (12.5%), had costs greater than $6,000. The average cost per individual in this group was $1,705.88.

Group IV had six respondents with injuries in the thoracic 7 to thoracic 12 range. The percentages were similar to group I with five (83%) individuals having out of pocket expenses of $2,000 or less. The remaining one person (17%) had expenses in the $4,001 to $6000 range. The average for out of pocket costs per individual in this group was $1191.67 which is considerably higher than the average cost in group I.

In group V, there were six individuals with injuries in the lumber 1 to lumber 5 range. Four (67%) individuals reported out of pocket expenses under $2,000 and two (33%) reported costs between $4001-$6000. The average was $871.67 per person.

Thirteen individuals did not identify their level of injury in the questionnaire. The average cost for this group was $1,455.31 per person.

One Way Analysis of Variance for Total Expenses and Level of Injury

A one way, ANOVA, was done for total expenses and level of injury. The null hypothesis was that there is no difference in total out of pocket expenses for the five groups based on categories for level of injury; i.e., Ho: $\mu 1=\mu 2=\mu 3=\mu 4=\mu 5$.

The alternate hypothesis is that all means are not equal. It was postulated that the higher levels of injury will have higher mean expenses.

The results show that the F ratio of 0.427 is not significant ($F=0.427$; $df=4,59$; $p=0.79$). Therefore, we fail to reject the null hypothesis that all group means are equal, and conclude that there is no difference in total out of pocket expenses for the five groups.

CHAPTER V

Discussion of Results

The following chapter provides a discussion of the data presented in this study.

Limitations

A number of limitations must be considered when interpreting the findings of this study. Sample size was a limiting factor in this study for two reasons. First, when the 77 cases were subdivided into groups some of the groups had small n's. Secondly, the response rate of 15% limits the possibility that the sample was representative and therefore limits generalization of the results to the population of all spinal cord injured persons in Alberta.

In order to compare the expenses for employed and unemployed individuals two groups were used.

The sample sizes for the t test, n = 26 and n = 49 were quite different. While a sample size of 49 is considered quite large, a n of 26 is considered to be small. Champion (1970) claims that "approximately 30 cases seem to be a bare

minimum" (p.91). The larger the sample and the closer the n's are to being similar, the more accurate the result.

The sample sizes for the level of injury, when broken down into groups, were also quite small as well as variable in number. While analysis of variance may be used for comparisons of small groups it is best to have larger n's in each group.

The questionnaire developed for this study also presents a number of limitations. Poor response rates yield small sample sizes reducing the possibilities of generalization of results to a population.

Berdie and Anderson (1974), questionnaire researchers, also cite poor quality of response as a major drawback with survey questionnaires. The quality of response is discussed in particular with the reported out of pocket expenses section. First, not all direct costs have a category listed (i.e., transportation, health care and housing adaptations are missing). Some respondents included housing adaptations under miscellaneous; however, it is possible that respondents may have missed including these costs. Second, it is possible that dollar amounts may not be completely accurate as individuals may easily miss expenses paid out over a year's time simply because the expense was forgotten. Another

possibility is that persons may not consciously realize that certain expenses are incurred as a result of their disability. This is especially true for persons who have been injured for a long time. It would have been advantageous to provide a list of examples of possible expenses to minimize these questionnaire limitations.

The problem with sample size is not so easily corrected. It is quite possible, however, that a larger sample could be obtained in one of two ways: 1) Survey all 1500 persons registered with the CPA, or 2) Use a different method to obtain information such as an interview format. These other methods suggest more expensive research.

Berdie and Anderson (1974) also discuss three other limitations that possibility affect return rates of questionnaires. These include persons that may be annoyed with questionnaires because they receive them too often, as may be the case for persons belonging to certain special interest groups. Others may feel that questionnaires are too impersonal. The third reason for personal prejudice against questionnaires may be that individuals feel data obtained in this manner are unscientific.

Anonymity of subjects, which is a consideration for

research on costs, can be viewed either as an asset or liability. Anonymity is an asset because of the personal nature of the financial data (i.e., income, government support received, etc.). It was expected that more accurate data would be forwarded if the individual felt secure that the researcher didn't know his identity. The liability is that low response rates could not be improved by methods of follow up known to work, such as personalization or veiled threat (Andrews,1978) as there was no way of identifying which individuals had not responded.

Concern over low response rates results from the need to obtain a representative sample of the population (Rubinson & Neutens,1987). With a low response rate, the representativeness of the sample for the population is unknown.

Studies on the effect of low response rates and data bias have reported contradictory findings. One study found demographic and socioeconomic differences between respondents of a questionnaire and nonrespondents (Hochstim & Athanasopoulus, 1970). Another study by Mayer and Pratt (1967) also found differences between different categories of nonrespondents. Andrews (1978) found differences in data in several categories of respondents when various prompting follow up methods were used to increase response rates to a

questionnaire on educational needs of registered nurses.

Conversely, McDonagh and Rosenblum (1965) found answers to questions were not greatly different between groups. Their study matched data collected by interview from nonrespondents of a questionnaire to the data given by respondents of the questionnaire.

Studies finding differences between respondents and nonrespondents have traditionally compared only demographic data. For some study purposes, differences, when they exist may not be relevant to the research questions; however, for the research study on costs of disability, demographics were relevant as was socioeconomic status which may have been related in a number of ways to the costs and income support for individuals.

Finally, this questionnaire had not been used in any other research and validity had only been established at face and content levels. While face and content validity are crucial to a questionnaire they are not considered to be the most reliable forms of validity by rigorous scientific researchers.

Discussion

Out of pocket cost

The majority of respondents (74%) reported having incremental expenses in at least one of the cost categories studied. These results are consistent with other studies that have examined incremental costs for individuals with a disability or families with a disabled member (Hyman,1977; Durward,1981; Robbins,1981; Piachaud, Bradshaw & Weale, 1981; Jacobs & McDermott, 1989).

The results on recurrent direct out of pocket costs found in this study are unique in Canada at present, so cannot be compared to any other Canadian cost study.

Out of pocket equipment expenses were shown to be the largest percentage of all costs surveyed in this study. Almost half (49%) of the sample reported equipment expenses ranging from $50 to $37,000. Equipment costs accounted for 38% of all costs reported, with an average cost per person of $3,129.00, third after the miscellaneous category mean of $3,971.00 (which included some big ticket price items like home renovations) and personal care with a mean of $4,153.00 .

While only half of the questionnaire respondents reported equipment costs in the year 1988 some individuals commented that they had out of pocket expenditures for wheelchairs costing several thousand dollars on a regular basis. Some estimates for wheelchair replacement were every 4-5 years .

Supplies and medications were the two categories with the second highest frequency of reported costs. Each category had thirty five percent of the respondents report having out of pocket expenses for supplies or medications.

While equipment, supplies and medication expenses were expected to be the most commonly reported, the average cost per person was found to be the highest for personal care ($4,153). This suggests an inequity exists for a smaller number (17%) of individuals that require personal care but must pay for it themselves. Although personal care costs are very high they are a necessary expense for those individuals who are unable to qualify for assistance through program benefits.

In Alberta, as of July 1991, Home Care services were expanded to include persons under the age of 65 years. The changes made to the Home Care program will allow more individuals to qualify for personal care assistance at home and will hopefully decrease expenses for individuals who previously

did not qualify for personal care services.

The miscellaneous category had the third highest percentage of respondents (32%) reporting and the second highest dollar average per person per year at ($3,971).

This category had the largest range of costs from $30 to $82,000. Miscellaneous covers everything from memberships in special facilities (Rick Hansen Centre) to major home renovations costing thousands of dollars. The high average cost per person can be explained by the high cost of home renovations/adaptations. This high cost may not be accurately reflected in this study as the time period of 1988 only reports home adaptations made in that year. Home modifications are probably the largest single out of pocket expense that an individual will have. The large dollar sum often requires families and/or spouses to make sacrifices to pay the bill and affects everyone's quality of life. While there are home modification grants available, some persons may still have costs in this area if their home requires a great deal of adaptation or if they only qualify for small assistance packages.

It must be noted that all out of pocket expenses are likely to affect others who are living with the disabled individual as family incomes are a finite resource, and expenses in one area

have ramifications for spending in all other areas.

All cost categories showed large ranges in costs reported, which emphasizes the great variability of out of pocket costs for different individuals and suggests that coverage of costs and income support are not equal for all persons with spinal cord injury.

The question arising from the original data, which show a majority of individuals as having incremental out of pocket costs, is why there are some individuals (26%) who reported zero expenses while others reported expenses in the thousands of dollars.

It is not surprising that disabled individuals have out of pocket expenses however it was somewhat unexpected to have twenty(26%) of the respondents report zero expenses. Further examination of some of the variables that might have been a common denominator for this group were inconclusive.

It was postulated that persons receiving certain income sources would likely have fewer costs. Workers compensation (WCB) was thought to be an income source that might cover all costs. This hypothesis was not supported for this sample as none of the individuals reporting zero expenses received WCB. The majority (40%) received AISH. The other 60% received

income from various sources including Canada Pension and salary. Salary level was then evaluated as it was thought that coverage through other programs such as Alberta Aids to Daily Living might cover more for those receiving low salaries. Salary level was not an indicator either, as only two individuals of the four reporting salary received incomes below $10,000 annually. The other two individuals reported incomes of over $30,000 annually.

The one variable that most individuals in this group had in common was living arrangement. Ninety percent of persons reporting zero expense were living with someone. This was not considered significant; however, as many individuals reporting expenses in excess of $2,000 also reported that they lived with a spouse or family member.

It was then postulated that level of injury may have a relationship to the zero expense group. This was not found to be an indicator either as the levels of injury for those reporting zero expense were representative of the larger sample (as shown in TableIV-5). Further discussion on level of injury and out of pocket expense is found in another section of this chapter.

Marital status, sex, and age were also found to be

representative of the larger population.

No conclusions could be reached as to a common variable for the 26% of the respondents reporting zero costs.

Some possible explanations are discussed under limitations. They include the possibility that certain expenses are forgotten over the long time period of one year, or that supplies or medications purchased are not associated with the disability.

Another explanation might be that services and/or equipment items needed for a better quality of life or increased independence are simply not purchased because the individual and/or family cannot afford them.

Employment, Unemployment and Out of Pocket Costs

Results on out of pocket costs for employed and unemployed individuals showed no statistically significant differences in mean total costs. It would appear that for this sample that out of pocket expenses examined in this study do not differ significantly for employment status.

These results must be accepted cautiously as differences in out of pocket costs may be significant if other variables or costs were included. Costs that may capture the

differential expenses may not be the costs examined in this study. Transportation or medical expenses may be quite different for employed and unemployed individuals. Other possible examples are medical premiums and dental costs that may not be covered for employed persons, while persons receiving AISH do have coverage for these expenses. Transportation costs may also be greater for employed persons who require specially adapted vehicles or daily taxi rides.

It is believed that increased costs and decreased benefits provide a strong disincentives for some individuals to seek employment. The absence of a statistically significant difference for this study does not negate this belief. While no differences in costs were found in this study, it is likely that the many other barriers to employment, such as inaccessible transportation and work environments, faced by disabled persons are as significant a deterrent to seeking employment as are the financial disincentives.

The data presented in this study are not comprehensive enough to present an argument for whether expenses are inequitable for employed individuals and therefore, provide disincentives to seeking employment. However, the data provide a rudimentary bank of knowledge showing the financial

burden associated with disability. Further comprehensive study is necessary in this area, as employment in relation to quality of life is a significant issue in society today.

Level of Injury

There were 64 individuals who were put into one of five categories based on the identified level of injury. Thirteen respondents did not indicate level of injury and these were treated as missing values in the statistical analysis. For these results we failed to reject the null hypothesis which states there is no difference in mean costs for the five groups studied. The statistical test used was a one one analysis of variance.

The results of this study must be accepted cautiously as the overall sample size (N=64) is relatively small and when broken down into the five groups the n's of three groups (each with only 6 subjects) are especially small. The largest group with an n of 30 was group II, those with cervical 5 to cervical 8 injuries, classified as quadriplegic.

The expenses for this group showed that 60% of these individuals had costs of less than $2,000 however 20% reported costs of over $6,000. The only other group to show expenses

over $6,000 was group III with thoracic 1 to thoracic 6 level injuries. This group had the second highest number of respondents n=16 and had 13% of those respondents reporting costs exceeding $6,000.

Group I, considered high quadriplegics (C1-C4), showed 83% as having costs under two thousand dollars. It was speculated that because of the high level of injury resulting in low functional abilities these individuals may be living in institutional or group home situations where higher coverage for needed supplies and attendant care is provided; however, this was true in only two(30%)of the cases.

Furthermore, group IV with low thoracic (T7-T12) lesions, showed similar results to group I (83% had costs < $ 2,000).

Average costs calculated for each group showed no explainable pattern either. Ranges for each group were large and variable from a low range of $2,425 (group I) to a high of $119,625 (group II). Therefore one cannot conclude any relationship of costs to level of injury with these data.

These results are different from studies previously reported. Humphreys (1978) estimated that average lifetime care cost were higher for quadriplegics that for paraplegics. Young (1982) supported these findings when he reported that

"high quadriplegics have the highest cost and incomplete paraplegics the lowest" (cited in Adelstein, p.32). The results reported by Young and Humphreys are not directly comparable to this study as their focus was on initial medical/rehabilitation period costs, while this study focuses on out of pocket costs after discharge.

It is quite conceivable that the numerous variables affecting income, benefits and out of pocket expenses are all interrelated. Consequently, examining individual variables on small samples provides somewhat inconclusive information at best. It is recommended that future studies examining out of pocket expenses use larger samples and examine a number of variables at a given time.

This study can conclude only that the majority of disabled persons had out of pocket costs. Conclusions made regarding differential relationships for employment status or level of injury and direct out of pocket expenses were that there was no difference in the costs studied.

One final comment seems appropriate. While no differences in costs for the single variables examined were found, the data clearly indicate that persons with disabilities do carry a substantial incremental financial burden as do their

spouses and families.

Even for persons reporting expenses of less than $2,000 the relative expense or proportion of their expenses to their income must be noted. If 67.5% of disabled persons, employed and unemployed, have yearly incomes of less than $20,000 then $2,000 (10% of yearly income) in out of pocket expenses is a significant financial burden. Finally, only a proportion of the incremental costs were studied for this thesis leaving a major research question to be answered: What are the total out of pocket costs for spinal cord injured persons in Alberta?

CHAPTER VI

Summary and Conclusions

Summary

This study was based on three questions concerned with incremental, recurrent, out of pocket expenses for individuals with spinal cord lesions due to traumatic injuries.

Data obtained by survey questionnaire provided information on out of pocket expenses for a sample of 77 spinal cord injured individuals. The respondents reported expenses in one or more of the following categories: equipment, medication, supplies, nursing care, personal care, homemaker, other (handyman, maintenance, occupational and/or physiotherapy services), education and miscellaneous. The miscellaneous category included some home adaptation costs in the year 1988 as well as numerous other costs such as memberships in special associations such as the Rick Hansen Centre.

Data show a majority (74%) of the sample had expenses in at least one of the categories included in this study. Twenty six percent of the respondents reported zero costs for the expenses listed in this study. For approximately one quarter of the sample that did not have expenses in one of the listed categories a number of variables were examined to see if there

was any commonality apparent for this group. Of the variables examined only one, living arrangement, was found to be applicable to almost all of this group. Ninety percent of the individuals who reported zero expenses also reported living with someone (not alone). However, this was not considered significant as 88% of the sample also reported living arrangement as living with family, spouse, or other (not alone).

The question still remains as to why some individuals reported zero expense while a majority of individuals reported out of pocket expenses in at least one category.

The second research question was; Do employed disabled individuals have different expenses than unemployed disabled persons? A t test for difference of means was run on the total costs for the two groups. Employed persons (group I) had 26 respondents and unemployed persons (group II) had 49 respondents. The employment status of two respondents was unknown. No significant difference in costs were found for the two groups.

The third question posed was whether there was a relationship between the level of injury (spinal lesion) and total cost per person. In order to test whether there was any significant difference in means for the five groups based on level of spinal lesion a one way analysis of variance was conducted. The result showed no difference in costs for the five

groups evaluated in this study.

Conclusions

Conclusions presented in this study are limited by the data available, the sample size and the retrospective method used for data collection. The small return rate(15%) and resulting small sample(N=77) raise concern for the representativeness of the sample. Questionnaire bias may also be a concern as it was noted that the level of education was higher in the sample than it was in the study. Results discussed in this study cannot be generalized to the spinal cord population as external validity cannot be established with the small sample and the possible questionnaire bias.

A second major limiting factor that must be considered when reviewing the conclusions in this study is the accuracy of the expenses reported. The retrospective method used for data collection, over the period of one year, may not have provided the most accurate expense reports as memory may fail when purchases are recalled over a long period of time. In spite of the limitations discussed some statements can be made based on the findings.

The majority(74%) of the individuals in the sample had incremental out of pocket expenses in at least one of the direct recurrent cost categories included in this study, in the year

1988. The reported costs in each category had large ranges and therefore variations in costs were found to be great for disabled individuals.

These results suggest, first, that disabled persons with spinal cord injuries have very individual needs and that they are not a homogeneous group. Second, that the great variability in expenses for all categories suggests that the program benefit and income system is inequitable for disabled persons. The result of the inequitable system is that some individuals have proportionately greater financial burdens.

Conclusions about differences in costs to disabled persons with spinal cord injuries who are employed were not made in this study as statistical results may not be accurate due to variability of sample sizes and costs reported.

The same statement can be made for differences in expenses for groups categorized by level of spinal lesion as three of the sample groups had n's of only 6. A sample n of at least 30 is thought to be an acceptable number for providing statistically sound results.

The results in this study also show that individuals with spinal cord injuries living in Alberta do suffer financial burdens as a result of their disability. While 69% of the individuals reported costs below $2,000 for the year 1988 these costs must be understood in relation to income levels that for the most part

are below the national poverty level. The percentage of income spent on needs resulting from disability varies from 10% of income to a reported 100% of income suggesting that other needs are provided for by families and/or spouses. In many cases it may also mean that needs remain unmet and that quality of life and independence suffers as a result.

Generalizations of results to the spinal cord injured population can only be made with extreme caution. There are numerous variables and demographic characteristics that are unknown about the population; therefore the representativeness of this sample is questionable.

The complex nature of issues relating to the disabled Canadian require comprehensive data collection and study. Examination of singular variables such as the cost and employment status in this study cannot provide conclusive results. There are so many interrelated variables that to examine only one variable ultimately produces more questions than answers. Further study, in the area of costs as they relate to disability, is imperative if progress in providing independence to disabled persons is to be made.

Recommendations for Future Study

The research examined in this study revealed a number of areas which are recommended for future study.

Recommendations arising from this study fall into two major categories.

The first category encompasses future research on personal and family costs associated with disability. While this study focused on specific direct out of pocket costs for persons disabled by traumatic spinal cord injury, there are numerous other causes of disability which may have significant financial impact on those persons affected. Concomitant with the need to study the costs and personal expenses of other disabling conditions is the need to expand the costs studied. For example transportation costs, health care costs and housing adaptation costs were not directly included in this study; however, they may have significant importance to personal cost.

A second area recommended for future study is the relationships that various levels of income and expense have on the quality of life for the disabled Canadian. This area of research is intimately related to the study of minimizing handicaps created by environmental factors. How the environmental handicaps can best be minimized, through the effective use of financial resources, and by whom is a timely question.

How can resources be most effectively allocated in order to decrease or remove the environmental barriers that create handicaps? Research in these areas has been undertaken in

other countries; however, it is critical that Canadian research be completed in order to provide relevant information to the policy makers.

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APPENDIX A
COVERING LETTER

March 7, 1990

Dear Sir/Madam:

I am writing to ask for your assistance in the completion of a questionnaire on out of pocket expenses that individuals with spinal cord injuries have. The many financial problems faced by individuals with spinal cord injuries are often discussed, however there is very little documented information that is useful in decision making or public policy development.

Some of the questions this study hopes to answer include; What out of pocket expenses do persons with spinal cord injuries have? Do employed individuals have more out of pocket expenses than those who are not employed and if so is this a disincentive to obtaining employment? Are there differences in financial assistance programs which are dependent on how or where you were injured?

Your help is needed in completing this questionnaire. The more responses received the more useful and accurate the results

will be. Answer questions as honestly as possible. If you do not know the exact amounts you may estimate. All responses are anonymous.

This questionnaire is part of a thesis for the Masters degree in Health Services Administration being completed by myself, Darlene Nadane. If you wish to obtain a copy of the results of this study please phone or write to myself at the address listed below.

If you have any questions or concerns please call tam Parker at the CPA Edmonton 438-5046, or Randy Arndt, CPA Calgary 236-5060.

The questionnaire is a self mailer, simply fold in half and drop in the mail.

Please return this questionnaire on or before April 6, 1990.

Thanking you in advance for your valuable time and assistance.

Sincerely,

Darlene Nadane

206 Hollands Drive
52450 Range Road 222
Ardrossan, Alberta
T0B 0E0

Phone: (403) 922-5505

APPENDIX B

QUESTIONNAIRE

QUESTIONNAIRE: OUT OF POCKET COSTS FOR INDIVIDUALS WITH SPINAL CORD INJURIES

The issues of individual costs is very important to disabled policy development as it is an area that has been overlooked to date. Your assistance in providing information requested below is crucial to accurately determining the personal costs to the person with a spinal cord injury. Thank you for taking the time to complete and return this questionnaire.

General Information

Please fill in the blank or check ___ the box which most closely describes your best answer to EVERY question.

1. What is you sex? ___ Male ___ Female
2. Age ___
3. What is the highest grade you completed in school?
   Grade ___ College/University ___
4. What is your martial status? (Consider a common-law relationship as being married.)

___ Married (or commom-law) ___ Single (divorced, separated, widowed)

5. Present accommodation (Check all relevant boxes)

___ House or apartment ___ Acute care hospital

___ Apartment ___ Nursing Home

___ Accommodation with services ___ Auxiliary

___ Group home/ transitional facility ___ Rehabilitation hospital

___ Other accommodation (please specify) _____

_____

6. Present Living Arrangement

___ Alone ___ Family member ___ Other

7. Level of Lesion

___ C1-C4 ___ T1-T6 ___ L1-L5 ___ Complete

___ C5-C8 ___ T7-T12 ___ S1-S5 ___ Incomplete

___ Other injuries if applicable: _____

8. What year were you injured?_____

9. How were you injured?

___ Work accident ___ Recreational accident

___ Motor vehicle accident ___ Work accident (self-employed)

___ Other (please specify)_____

_____

10. Employment (Please check numbers that apply to you)

___ I am presently employed

___ I am presently seeking employment

___ Other (not presently seeking employment, student, retired, etc.)

11. Please check one of the categories for your 1988 income from employment (before deductions):

___ Less than $ 5,000

___ $ 5,000 - $ 9,999

___ $ 10,000 - $ 14,999

___ $ 15,000 - $ 19,999

___ $ 20,000 - $ 24,999

___ $ 25,000 - $ 29,999

___ $ 30,000 - $ 34,999

___ $ 35,000 - $ 39,999

___ $ 40,000 - $ 44,999

___ $ 45,000 - $ 49,999

___ Over $ 50,000

12. Employment status of spouse or common-law partner

___ Not applicable/not married

___ Employed

___ Spouse's 1988 annual income (before deductions) _____

<u>Definitions</u>

Out of Pocket: is cash paid out by the disabled individual for equipment, supplies or services required because of that person's disability. Out of pocket expenses do not include services, supplies or equipment received through special , grants funding organizations or other third party payers.

Income: "money" received from various sources during a given period (for 1988) such as wages, salary, benefits or payments from programs or disability insurance.

For 1988, please provide your best estimate of various costs resulting from your disability.

13. Equipment Out-of-Pocket Expenses for 1988 _____

14. Supplies Out-of-Pocket Expenses for 1988 _____

15. Medication Out-of-Pocket Expenses for 1988 _____

16. Personal service: Please check which services you receive and fill in the cost (with your best estimate)

	Amount Paid Out-of-Pocket in 1988
___ Nursing (Registered Nurse)	_____
___ Personal Care (RMA, Personal Care aids or attendants) (Include room & board costs, etc.)	_____
___ Homemaker	_____
___ Other (handyman services, home maintenance, PT OT expenditures exceeding coverage, etc.)	_____

17. Miscellaneous Out-of Pocket Expenses _____

18. Are you presently enrolled in any educational activities that result in additional costs (over and above usual costs such as tuition and books, etc.)? _____

Amount paid Out-of Pocket _____

19. Home modification: Year modification made _____

20. Have you required vehicle adaptations? ___Yes ___No

Year adaptations were made_____

21. What, if any, INCOME Sources were you receiving in 1988? Please check.

	Yes	Amount (if known)
1. AISH	____	_____
2. Workers Compensation	____	_____
3. Insurance (private)	____	_____
4. Canada Pension	____	_____
5. Social Assistance	____	_____
6. Other (please list any other personal income from other sources	____	_____

22. In 1988, did you receive any assistance for equipment, supplies or services from any programs or organizations? (Other than those listed above.)

___ Easter Seals Ability Council (equipment)

___ Alberta Aids to Daily Living

___ Medical Services Branch

___ Motor Vehicle Accident Claims

___ Other (please specify) _____

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